
INSTITUTE FOR BIOETHICS,
HEALTH POLICY AND LAW

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HUMAN GENETICS AND THE FEDERAL COURTS: EMPLOYMENT, INSURANCE AND SCHOOLS

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- I. What is genetic discrimination?
- II. Should genetic discrimination be regulated separately?
- III. What are the legal issues?
 - A. Employment
 - B. Insurance
 - C. Schools

I. What is genetic discrimination?

What is “genetic”?

What is “discrimination”?

What is “genetic”?

We use genetics every day to differentiate among people.

For example, when we select the tallest player to be the center on our basketball team we are using genetics.

But, this is the *expression* of genetics – phenotype.

The promise and peril of the new technology is that we can identify genetic characteristics of people before they are expressed, or even if they are never expressed.

This is called genotype.

GENOTYPE = PREDICTIVE GENETICS

Privacy and discrimination concerns are caused by lag times

1. The lag time between the identification of the genetic predisposition and the date of possible onset of symptoms.

(Individual lag time).

2. The lag time between the ability to identify genetic markers of predisposition to illness and the ability to prevent, treat, or cure the condition.

(Societal lag time).

WHAT IS DISCRIMINATION?

It is more than just drawing distinctions. In common usage and in legal terms it refers to drawing distinctions based on invidious, unfair, or socially unacceptable criteria.

CONCERNS ABOUT GENETIC DISCRIMINATION

1. Predictions are inaccurate
2. Predictions are accurate

Categories of discrimination

	<u>Rational</u>	<u>Irrational</u>
Acceptable	<p>Choosing an employee based on relative skill or other job-related criteria</p> <p>Choosing an employee based on medical assessment of ability to perform the job</p>	<p>Choosing an employee based on Zodiac sign</p> <p>Choosing an employee based on a coin toss</p>
Unacceptable	<p>Excluding a person with cancer from consideration for employment based on concerns about health care costs</p> <p>Excluding a pregnant woman from consideration for employment because she may soon go on maternity leave</p>	<p>Excluding a person from consideration for employment based on religion (in a secular enterprise)</p> <p>Excluding a person from consideration for employment based on national origin</p>

SHOULD WE ENACT SEPARATE LAWS TO DEAL WITH GENETIC DISCRIMINATION?

(This is referred to as
“genetic exceptionalism”)

- “Genetic” is impossible to define
 - If it excludes family history it is too narrow
 - If it includes family history it is too broad
- As a scientific matter, “genetic” is increasingly irrelevant, because virtually all disorders have a genetic and an environmental component



Since the Human Genome Project began in 1990:

- At least 43 states have enacted laws prohibiting “genetic” discrimination in health insurance
- At least 32 states have enacted laws prohibiting “genetic” discrimination in employment



- Other state laws prohibit “genetic” discrimination in life insurance, protect “genetic” privacy, and regulate “genetic” testing
- Bills in Congress would bar “genetic” discrimination in health insurance and employment

LEGAL ISSUES

Employment

Starting point is the Americans with
Disabilities Act (ADA)

Medical Examinations Under the ADA

1. Preemployment
Prohibited by § 102(d)(2)

Medical Examinations Under the ADA

2. Preplacement

- Authorized by § 102(d)(3)
- Unlimited in scope
- May require release of all medical records
- Withdrawal of offer (based on medical exam) only permissible if unable to perform essential functions

Medical Examinations Under the ADA

3. Employment

- Limited by § 102(d)(4)
- Either job-related and consistent with business necessity or voluntary.

NORMAN-BLOODSAW v. LAWRENCE BERKELEY LABORATORY 135 F.3d 1260 (9th Cir. 1998)

Clerical employees of LBL later learned that at their preplacement medical examinations they were tested, without their consent, for pregnancy, syphilis, and sickle cell trait.

The court upheld their legal claims based on Title VII (race and sex discrimination) and federal and state constitutions, but affirmed the dismissal of the ADA claim because preplacement medical examinations may be of unlimited scope and there is no informed consent required by the ADA.

Definition of Disability Under the ADA

- (2) **DISABILITY**- The term “disability” means, with respect to an individual –
- (A) a physical or mental impairment that substantially limits one or more of the major life activities of such individual;
 - (B) a record of such impairment; or
 - (C) being regarded as having such an impairment.

ADA § 3(2), 42 U.S.C. § 12102(2).

EEOC COMPLIANCE MANUAL vol. 2

EEOC ORDER 915.002, § 902 (1995)

This part of the definition of “disability” applies to individuals who are subjected to discrimination on the basis of genetic information relating to illness, disease, or other disorders. Covered entities that discriminate against individuals on the basis of such genetic information are regarding the individuals as having impairments that substantially limit a major life activity. Those individuals, therefore, are covered by the third part of the definition of “disability.”

SUTTON v. UNITED AIRLINES, INC. 527 U.S. 471 (1999)

Supreme Court held that in considering whether an individual is covered under the ADA, the individual should be considered in his or her "mitigated" state. Also, (1) the Court need not defer to EEOC's interpretation of the ADA, and (2) the ADA was intended to have limited coverage of 43 million individuals with severe impairments.

CHEVRON U.S.A. Inc. v. ECHAZABAL, 536 U.S. 73 (2002)

The Supreme Court held that it was lawful for an employer to apply the direct threat defense to an individual with hepatitis C who was excluded from a job with chemical exposure because of concerns that workplace exposures would damage his own health.

Does it violate state laws prohibiting genetic discrimination?

- 30 states have laws prohibiting genetic discrimination in employment
- They also prohibit employers from making genetic testing a condition of employment
- These laws do not prohibit employers from requiring a release of all medical records

BURLINGTON NORTHERN CASE

On February 12, 2001, following a suit brought under the ADA by the EEOC, Burlington Northern Santa Fe Railroad announced that it will no longer require employees who have submitted claims of work-related carpal tunnel syndrome to provide blood samples for genetic testing.

Brotherhood of Maintenance of Way Employees v. Burlington Northern Santa Fe R. Co., 2001 WL 788738 (N.D.Iowa 2001)

EEOC's case was based on the argument that only medical tests with demonstrated clinical utility are "job-related and consistent with business necessity" under § 102(d)(4) of the ADA.

This issue has never been resolved in court.

The problem in *Burlington Northern* is not that the employer was doing genetic testing, it is that the employer was requiring medical procedures without informed consent and using a medical test that was inappropriate for the workplace and not designed to benefit the health of the employees.

LEGAL ISSUES

Insurance

1. Health
2. Life
3. Disability
4. Long-term Care

GENETICS AND HEALTH INSURANCE: FEDERAL LEGAL ISSUES

A. Eligibility

Health Insurance Portability and Accountability Act (HIPAA). 42 U.S.C. §§ 300gg to 300gg-2, provides that genetic information may not be treated as a preexisting condition, and may not be used to limit the eligibility of an individual to enroll in any covered plan. *Id.* § 300gg(b)(1)(B), § 300gg-1(a)(F).

B. Coverage Decisions

In Pegram v. Hedrich, 530 U.S. 211 (2000) and Rush Prudential HMO, Inc. v. Moran, 536 U.S. 355 (2002), the Supreme Court has indicated less willingness to hold that state court actions involving treatment decisions are preempted by ERISA. This will be a continued source of litigation, and may involve issues related to genetics.

Katskee v. Blue Cross/Blue Shield, 515 N.W.2d 645 (Neb. 1994) (rejecting claim that plaintiff's genetic predisposition to breast-ovarian cancer was not an "illness," defendant was ordered to pay for prophylactic hysterectomy and bilateral salpingo-oophorectomy).

Future cases are likely to involve whether genetic testing, gene therapy, and pharmacogenomic-based medications are “experimental” or “not medically necessary.”

LEGAL ISSUES

Schools

A variety of genetic conditions have been identified that may affect the way students perform academically and socially in school settings from pre-K through graduate and professional schools.

1. Educational purposes – diagnosing dyslexia through non-genetic means usually occurs after age 8, but genetic analysis could lead to more appropriate educational interventions earlier.
2. Behavioral problems and discipline – children with fragile X syndrome, if identified, can be helped through behavior management and medication

3. Health impairments – providing appropriate medical services and therapy would be aided by more accurate diagnoses
4. Public health screening – schools might begin testing for genetic predisposition to certain childhood cancers or neurological disorders, in addition to dental, vision, hearing, TB, and other tests now performed

5. Documenting accommodations – genetic evidence of attention deficit hyperactivity disorder (ADHD) may be used in deciding on accommodations for tests
6. Admissions and placement – genetic evidence of cognitive ability or behavioral genetic traits could be used in “tracking” students in school or in admissions to college or graduate school

Titles II (public services) and III (public accommodations) of the ADA

Section 504 of the Rehabilitation Act

Individuals with Disabilities Education Act (IDEA)

Doe v Knox County Board of Education,
918 F. Supp. 181 (E.D. Ky. 1996) (13
year-old “hermaphrodite” girl stated claim
for violation of the Family Educational
Rights and Privacy Act (FERPA), 20
U.S.C. § 123g, and the U.S. Constitution
where her name, diagnosis, and the
results of her “private” due process
hearing were published in the town
newspaper).

Judge Jennifer Coffman decided the case.

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